Patient Education and Counseling 98 (2015) 364–369

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Patient education

Reproductive knowledge and patient education needs among Indonesian women infertility patients attending three fertility clinics

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ARTICLE INFO

Article history:
Received 29 April 2014
Received in revised form 27 October 2014
Accepted 13 November 2014

Keywords:
Infertility
Indonesia
Patient education
Patient knowledge
Information sources

ABSTRACT

Objective: This study investigated the reproductive knowledge and patient education needs of 212 female Indonesian infertility patients.
Methods: A cross-sectional survey was conducted from July to September 2011 by married women, 18 to 45 years old, seeking infertility care from clinics in Jakarta, Surabaya and Denpasar. Participants were literate, the sample was highly educated, predominantly urban and primarily middle class or elite.
Results: Infertility consultants were cited as the most useful source of information by 65% of respondents, 94% understood that infertility results from male and female factors, 84% could distinguish between infertility and sterility, and 70% could identify their fertility window. However, demand for further knowledge of reproduction and infertility was expressed by 87%. Patients' knowledge of the causes and treatment of infertility was extremely poor. Two key causes of infertility, advanced age and untreated sexually transmissible infections, were not named. Only 19% of patients had received written information.
Conclusion: The study revealed the need for expanded infertility patient education among women patients accessing fertility care in Indonesian clinics.
Practice implications: Opportunities for education should be maximized within infertility consultations. A standardized infertility patient education curriculum should be developed, incorporating patients' priorities, as well as gaps in existing knowledge.

1. Introduction

Provision of patient education has long been recognized as key responsibility of health care providers and as fundamental to patient empowerment. Ensuring that patients are adequately informed is essential to safeguarding minimum standards of care [1], promoting the highest quality of care [2] and providing patient-centered care [1]. The flow-on effects include ensuring patients' ability to give informed consent, greater understanding of and participation in medical decision making and often better health outcomes [3]. Moreover, patient education has been found to be a key aspect of patient satisfaction with infertility care [4–6].

While there is widespread acknowledgement of the importance of patient education within the infertility field, there is limited research into what knowledge infertility patients actually possess and how they gain infertility related information in resource poor settings where health literacy is typically low. Most research on the knowledge levels and needs of infertility patients has been conducted in Western industrialized settings [1,7], often focusing on patients' use of the internet for accessing information [8]. The current gap in understanding of fertility patients' knowledge in non-Western and developing country settings is enormous. This article reports on the first study that has investigated Indonesian infertility patients' reproductive knowledge, information sources and education needs.

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http://dx.doi.org/10.1016/j.pec.2014.11.016

Estimates of infertility in Indonesia vary depending on whether they are extrapolated from the number of patients seeking biomedical care or whether they are derived from demographic health surveys. The lowest rate quoted is 10% and the highest is 22% [9]. Regardless of the difficulties in establishing accurate infertility rates in Indonesia the significance of infertility in terms of the real numbers affected cannot be understated. Based on the current population of women of reproductive age, a conservative 10% female infertility rate translates into a sub-population of around four million women experiencing infertility in their life time [9]. Enormous social suffering stems from childlessness in Indonesia, and impacts upon women to a greater extent than men due to centrality of motherhood for female identity [10].

Biomedical fertility care and assisted reproductive technologies (ART) have been available in Indonesia since 1987. However, the past five years has seen unprecedented expansion in the capacity of infertility clinics. In 2009 there were nine registered fertility clinics operating across the country compared to a total of 23 clinics in 2013, and in 2012 the number of IVF cycles performed was 3581 compared with 987 cycles recorded for 2009, representing an increase of around 400%. This escalation in the number of Indonesians accessing infertility care and seeking to explore the option of ART amplifies the responsibility of the Indonesian infertility field to ensure that these patients are adequately educated.

Debates over the rationale for and against the provision of ART in developing countries have often raised concerns over ensuring quality of care in relation to high-tech treatments [11,12]. Considering that the infrastructure of Indonesian fertility clinics can be described as state of the art, and that the technical expertise of ART clinicians in Indonesia is closely monitored by government and professional bodies, concerns over technical competence are somewhat misplaced. Rather, it is the interpersonal communication between clinicians and infertility patients that requires investigation. As Dyer et al. have asserted in relation to infertility patients in South Africa; "the need for information is of such importance both to the individual patient and to the advancement of reproductive health . . .that information and counseling should be accessible even in the absence of other treatment options" [13]. This research represents an important contribution toward establishing the evidence required for developing a comprehensive education strategy for Indonesian infertility patients.

2. Methods

This study aimed to investigate Indonesian infertility patients' reproductive knowledge, information sources and education needs. The data was generated by the "Survey of Indonesian infertility patients' reproductive knowledge and health seeking behaviour," conducted between July and September 2011. This article reports on data from the knowledge and education components of the survey, as findings on patterns of health seeking have been published previously [9]. Our respondents were 212 infertile Indonesian women recruited through three infertility clinics in the cities of Jakarta, Surabaya and Denpasar. As funding was adequate only for the inclusion of three clinics, we selected clinics in hospitals with differing models and client bases. The Jakarta based clinic is in an elite private hospital that typically attracts patients of very high socio-economic status. The Surabaya based clinic sits within a university teaching hospital that tends to attract mid to lower income patients, while the Denpasar clinic is attached to a regional public hospital that primarily services those who cannot afford to pay for private services. Despite being recruited in these three cities, only 46% of the sample resided within the city or district where they were accessing fertility care, which is indicative of the high degree of mobility exercised by Indonesian infertility patients in seeking biomedical care [9].

Invitations to participate were posted in waiting rooms, inviting patients to contact clinic reception staff for information sheets. Information sheets provided details of the study and participation requirements and invited interested parties to contact survey interviewers by text message if they wanted to participate. No treating doctors were involved in recruitment to avoid potential feelings of obligation among patients. The sample was a self-selected convenience sample. The sample size constituted over 50% of women patients attending these clinics in between July and September. An exact response rate is impossible to verify as we were unable to know what proportion of patients actually read the invitation flyer, and we were careful to ensure that recruitment was via self-selection. The criteria for participation was that women be married, aged between 18 and 45 years, and seeking biomedical infertility treatment. Single women were not recruited because infertility care is only legally available to married couples in Indonesia. Women undergoing IVF programs were excluded to avoid any stress-related impact on their treatment that could stem from participation. Surveys were administered via face-to-face interviews conducted by a team of 14 female interviewers, all of whom were doctors, and who were trained in research ethics and interviewing techniques. None of the interviewers were the treating doctors of participants.

The proportion of respondents recruited was relatively even across the three sites—35% from Jakarta, 36% from Surabaya, and 29% from Denpasar. The sample was highly indicative of the privileged sub-population of Indonesians who have the easiest access to infertility care due to their affluence, proximity to services and higher education. The sample was comprised of 78% urban residents, with the remaining 22% living rurally or in poor urban fringe communities. The ages of respondents ranged between 18 and 45 years and the median age was 31. All respondents were literate and 86% had completed senior high school or some form of tertiary education, and 60% possessed a tertiary degree. Thus, the educational attainment of women in the sample was very high and not indicative of Indonesia's overall population. Monthly household incomes among our respondents were skewed toward higher socioeconomic groups with 50% being classified as middle class or elite on the basis of their monthly household income. See Table 1 below for additional description of sample characteristics. In sum, our sample was well educated, affluent and predominantly urban. This confirmed our presumption that women with lower incomes, less education and those living in more remote areas would be less likely to access infertility clinics, and subsequently would be less likely to be recruited.

The distinct nature of this affluent and highly educated sample reflects the fact that only around 10% of Indonesia's population fall within an income band where they could pay for fertility care out of their expendable income without relying on loans or savings. The high socio-economic status of the sample limits the generalizability of findings to other Indonesian women experiencing infertility who do not access biomedical care due to their relatively poor socio-economic status or remote location. This convenience sample therefore provides insight relevant only to the experiences and needs of a specific sub-population of infertility patients who are in a position to access and pay for biomedical infertility care available only in large cities.

The sample size for analysis was 212 and descriptive and categorical analysis was performed by two statisticians using STATA. Below we present our findings on a number of themes which are: sources of information about infertility, knowledge of reproduction and infertility, knowledge of the causes and treatment of infertility, written information provided to patients and requested information. These five thematic clusters of survey

Table 1
Socio-demographic characteristics of sample ($n = 212$).

	%
Age groups	
18–29 years	34
30–35 years	40
36+ years	25
Recruitment location	
Jakarta	35
Surabaya	36
Denpasar	29
Education level	
Primary school	2
Junior secondary school	2
Senior secondary school	26
Tertiary education (Bachelor or Master degree)	60
Other	10
Monthly cash income level in IDR (Indonesian rupiah)	
0–2 million	19
>2–5 million	32
>5–10 million	25
>10–15 million	10
>15 million	14
Ethnicity	
Javanese	35
Balinese	24
Chinese	12
Indonesian	11
Sundanese	5
Religious affiliation	
Muslim	50
Catholic	20
Other Christian	16
Hindu	24
Buddhist	2

questions were devised to generate information about current sources and levels of information among patients, to identify knowledge deficits, and to provide insight for developing a more comprehensive approach to patient education for Indonesian infertility patients.

Participants were provided with plain language information sheets and asked to provide voluntary informed consent. They were informed of their right to skip questions and to withdraw from participation before their de-identified data was stored. All interviews were conducted in private counseling rooms and took between 30 and 45 min. Ethics approval was granted by the La Trobe University Human Ethics Committee, the relevant ethics committees of the University of Indonesia and Airlangga University, as well as by the three hospitals involved as recruitment sites. Because we understood that patients were likely to have knowledge deficits improving their knowledge was considered an ethical obligation. Thus, following each interview, survey participants were given an information booklet in lay language which contained the correct answers to knowledge questions in the survey, and an overview of the prevalence, causes and treatment of infertility.

3. Results

3.1. Sources of information about infertility

Respondents were asked to list all sources of infertility information they had accessed prior to their most recent obstetrician/gynecologist (OBSGYN) visit. Patients provided multiple responses that yielded 13 categories of information sources. Table 2 below depicts the percentage of infertility patients who accessed the eight most popular sources of information, and patterns of access to those sources according to participant characteristics. The four most popular sources of information were OBSGYN—77%; friends—44%; the internet—31%; and family members—23%. Other less commonly reported sources of information that are not included in Table 2, were: midwife–7%; religious teacher or healer—4%; traditional birth attendant—3%; and the radio—2%.

Chi-squared tests were conducted to identify associations between respondent characteristics and the type of information sources accessed. Participants with a higher level of education and greater cash income were more likely to access information from the internet ($p \leq 0.001$) and magazines ($p = 0.018$), compared to those with lower education and less cash income. Participants with a lower level of education were more likely to access information from a GP ($p = 0.007$) compared to those with higher levels of

Table 2
Percentage of fertility patients who accessed various sources of information, by participant characteristics ($n = 212$).

	OBSGYN	Friends	Internet	Family member	Books	Magazines	TV	GP
Total sample	77%	44%	31%	23%	18%	16%	11%	10%
Age groups								
18–29 years	71%	40%	32%	21%	15%	15%	10%	10%
30–35 years	78%	52%	32%	27%	20%	14%	11%	7%
36+ years	83%	37%	30%	19%	20%	19%	11%	15%
p Value*	0.272	0.158	0.962	0.437	0.662	0.776	0.959	0.327
Education level								
Primary or Junior secondary school	60%	30%	0%	0%	10%	0%	20%	40%
Senior secondary school	82%	40%	11%	18%	7%	7%	7%	5%
Tertiary education	76%	42%	43%	27%	22%	17%	9%	9%
Other	76%	71%	29%	19%	29%	33%	24%	14%
*P value**	0.494	0.051	**<0.001**	0.167	0.053	**0.018**	0.111	**0.007**
Monthly cash income level in IDR (Indonesian rupiah)								
0–2 million	23%	25%	3%	8%	10%	8%	15%	18%
>2–5 million	18%	44%	26%	30%	20%	15%	12%	14%
>5–10 million	25%	47%	37%	24%	14%	12%	6%	2%
>10–15 million	38%	43%	52%	24%	29%	14%	5%	14%
>15 million	24%	62%	59%	24%	31%	38%	14%	4%
p Value*	0.456	**0.042**	**<0.001**	0.111	0.132	**0.010**	0.519	0.066

Note: Multiple response options were allowed.
* Chi squared test to determine if there is a statistically significant relationship between participant characteristics and sources of fertility information.

education, and participants with greater cash income were more likely to access information from friends compared to those with less cash income. Finally, a relationship between higher levels of education and accessing information from friends ($p = 0.051$) and books ($p = 0.053$) approached statistical significance.

Respondents were asked to identify the most useful source of information they had consulted, 65% ($n = 205$ due to 7 skips) reported OBSGYN as the most useful source, 18% reported that friends or family had provided the most useful information, while 8% identified the internet as the most useful source of information. Other responses were widely scattered across additional sources of information.

3.2. Knowledge of reproduction and infertility

A range of questions were asked to determine patients' basic levels of knowledge about reproduction and infertility. Responses are summarized in Table 3. Almost half the sample, 49% were able to give a medically correct definition of infertility. However, only 17% were able to estimate the prevalence of infertility in Indonesia (typically understood to be between 10% and 15%). The difference between sterility, being the permanent inability to have a child, and infertility was much better understood with 84% of respondents able to differentiate the conditions. The majority of patients (94%) correctly understood infertility as being caused by both male and female factors. 78% of the sample was able to estimate the typical duration of the menstrual cycle, and 70% were also able to calculate their fertile time during the menstrual cycle, while only 59% were able to identify any physiological signs of ovulation.

Chi squared tests were conducted to determine if there were any statistically significant relationships between patient characteristics and knowledge of reproduction and fertility. Results are detailed in Table 3. Higher levels of education were fairly consistently associated with greater levels of knowledge of reproduction and fertility. Participants with a higher level of education were more likely to be able to: correctly define infertility ($p = 0.016$), understand that infertility is caused by both female and male factors ($p = 0.004$), know the typical length of a menstrual cycle (≤ 0.001), calculate their fertile time during the menstrual cycle ($p \leq 0.001$), and know the physical signs of ovulation ($p \leq 0.001$). Age and income were typically not associated with greater knowledge, although those participants with higher levels of cash income were more likely to be able to calculate their fertile time during the menstrual cycle ($p \leq 0.001$).

3.3. Knowledge of the causes and treatment of infertility

Women were asked what they believed to be the causes of both female and male factor infertility. Despite the fact that all respondents had visited at least one OBSGYN, 10% reported that they did not know of any causes of male infertility and 11% reported they did not know of any causes of female infertility. The most common causes cited for female infertility were: menstrual problems—17%, tiredness or general poor health—12.5%, polycystic ovarian syndrome—11%, diet—8%, generic infections—7% (none specified sexually transmissible infections (STIs)), genetic factors—6%, and endometriosis—4.5%. The most common causes of male infertility cited were: poor quality sperm—30%, tiredness or general poor health—17%, low sperm count—16%, smoking—13%, genetic factors—3%, and poor diet—3%. Other causes of infertility cited varied widely and did not constitute any major categories.

Patients were asked to list any treatments for both female and male factor infertility that they knew of. Responses to these open ended questions were vague, difficult to categorize, and indicated a general lack of patient literacy in terms of describing medical treatments and interventions. 15% of respondents answered they did not know of any treatments for female infertility, while 18% reported not knowing any treatments for male infertility. The kinds of generalized answers that were given as treatments for infertility for both sexes included: consulting a doctor (29% for male infertility and 35% for female infertility), taking non-specified medicines (24% for male infertility and 22% for female infertility), and lifestyle changes (11% for female infertility and 15% for male infertility).

3.4. Written patient information

We asked patients whether they had ever received written information to take home about infertility from their most recent

Table 3
Percentage of patients with correct knowledge of reproduction and infertility, by participant characteristics ($n = 212$).

	Able to correctly define infertility	Knew the prevalence of infertility in Indonesia	Understood the difference between infertility and sterility	Understood infertility is caused by male and female factors	Knew the typical length of the menstrual cycle	Able to calculate their fertile time during the menstrual cycle	Knew the physiological signs associated with ovulation
Total sample	49%	17%	84%	94%	78%	70%	59%
Age groups							
18–29 years	49%	12%	86%	97%	74%	67%	51%
30–35 years	53%	15%	86%	93%	84%	78%	66%
36+ years	41%	26%	78%	93%	74%	61%	57%
p Value*	0.331	0.117	0.544	0.425	0.188	0.107	0.283
Education level							
Primary or Junior secondary school	20%	10%	50%	67%	50%	40%	10%
Senior secondary school	35%	9%	84%	93%	67%	42%	51%
Tertiary education	56%	21%	87%	97%	87%	85%	64%
Other	53%	19%	86%	95%	67%	67%	67%
p Value*	**0.016**	0.245	0.119	**0.004**	**<0.001**	**<0.001**	**<0.001**
Monthly cash income level in IDR (Indonesian rupiah)							
0–2 million	30%	13%	78%	90%	60%	30%	45%
>2–5 million	55%	12%	82%	95%	80%	79%	62%
>5–10 million	51%	25%	84%	94%	80%	80%	57%
>10–15 million	62%	24%	95%	100%	86%	76%	71%
>15 million	45%	17%	90%	93%	86%	79%	62%
p Value*	0.053	0.426	0.331	0.656	0.172	**<0.001**	0.568

* Chi squared test to determine if there is a statistically significant relationship between participant characteristics and knowledge of reproduction and fertility.

OBSGYN, only 19% answered yes. This sub-sample was asked to comment on the accessibility and quality of written materials. Their responses indicated that written information materials could be improved by: using non-medical language, clearly explaining medical terms, using more pictures, providing more detail of the different procedures used in infertility diagnosis and treatment, and covering a wider range of topics relating to infertility.

3.5. Requested information

When asked if they would like to receive further information related to infertility, 87% of patients answered yes. This sub-group (n = 184) were asked to elaborate on the type of information they desired. Their responses are summarized in Table 4. The most popular forms of information desired were: on the causes of infertility, requested by 25% of informants; how to conceive, requested by 20% of women; and how to improve fertility, requested by 15% of respondents.

4. Discussion and conclusion

4.1. Discussion

In our study, OBSGYN were identified as the source of infertility information accessed by the greatest number of respondents (77%), and as the most useful source of information by 65% of respondents. Similarly, Kahlor and Mackert found that 91% of 567 infertile women surveyed in the United States had relied on OBSGYN as their key source of information [8], while Thewes et al. found that 71% of a sample of 228 young Australian women diagnosed with breast cancer had sought infertility information from OBSGYN [14]. Moreover, in both these studies, OBSGYN were reported to be the most useful and preferred method of gaining infertility information, as is the case in our study. These results suggest that patient education within infertility consultations is highly valued by women infertility patients in Indonesia, just as it was for infertile women surveyed in Australia and the United States.

The main findings in relation to patient characteristics (depicted in Tables 2 and 3) suggest that overall Indonesian infertility patients with higher levels of education were more likely to access information (and from a variety of sources) and were also more likely to have greater knowledge of reproduction and infertility. This mirrors typical patterns of health-information seeking whereby education and income level tend to be associated with better access to health information [18].

While our study yielded a wide range of information sources accessed by patients, parallel studies identified additional sources not represented in our data. For instance, our respondents did not report patient support groups [8,14], online patient health records [15], patient decision making guides or self-education kits as sources of information [14]. These gaps reflect the reality that such education tools and information sources were not available in Indonesia at the time of research. None of the sample reported contact with infertility nurse educators or infertility counselors who commonly play important roles in infertility patient education in Western contexts.

Our data revealed a reliance on several information sources that are not typically present in studies based in Western secular societies. This included accessing religious leaders (4%), traditional birth attendants (3%) and friends (44%) as sources of infertility information. Reliance on these sources is indicative of a strong culture of medical pluralism that supports individuals' quests for seeking information and solutions to health problems both within and beyond bio-medical health systems. A study by Mostafa et al. in Saudi Arabia, another Muslim majority country, found religious leaders and traditional healers were common sources of infertility information among a sample of 144 infertile couples [16]. The expression of medical pluralism in much of Indonesia encompasses the validation of lay knowledge shared within local communities [17], reflecting the high reliance on friends (44%) as a source of infertility information in our study.

Qualitative research on infertility in developing countries has found that the biological processes of human reproduction are often poorly understood by women and men experiencing infertility [10,19,20]. The reported knowledge of female reproductive physiology among women patients in this study was substantially greater than we would expect among Indonesian women with fertility concerns who have never consulted an infertility specialist [10], which indicates effective patient education on this specific topic. In an Australian based study of fertility knowledge among women of reproductive age, only 32% of 385 women correctly identified the most fertile time during the menstrual cycle [21], compared to 70% of women who were able to identify the fertility window in our sample.

Knowledge about the causes and treatment of infertility was very poor within the sample. Two of the key causes of infertility, advanced age and untreated STIs, were not named by a single respondent. A lack of awareness of the significance of age for declining infertility has also been identified among childless women in Canada [22], women of reproductive age in Australia [21], and among university students in Sweden [23]. However, studies in more developed countries reveal a much greater awareness of STIs as a cause of infertility [21,22], compared to our results, which indicate no clear awareness of the threat of untreated STIs to infertility within our sample. This finding is of significant concern considering that untreated STIs are now recognized as the leading cause of female infertility worldwide [24], and the fact that rates of both chlamydia and gonorrhea in Indonesia have been steadily increasing in most at risk populations [25]. Lack of awareness that untreated STIs are a significant cause of infertility results from a systemic failure to explicitly address sexual health, and STIs in particular, within fertility care in Indonesia. The silence surrounding STIs in infertility consultations stems from the severe stigma associated with STIs and extramarital sexuality, and the subsequent desire of fertility consultants to avoid suggesting that their patients may have engaged in sexual behavior considered morally deviant [26].

Only 13% of respondents named smoking as a cause of male infertility, and none named smoking as a cause of female infertility, indicating a highly gendered understanding of smoking as an infertility risk factor. In Indonesian society, heavy smoking from a young age is normative for men, is positively associated with masculinity, and is endemic across both class and ethnic groups [27]. Considering that smoking is one of the most significant preventable causes of infertility in Indonesia [28], a much broader awareness of its impact on both female and male infertility should be integrated into patient education.

As the first research that has sought to explore Indonesian fertility patients' knowledge and patient education needs, this

Table 4
Types of information requested by patients (n = 184).

	%
Causes of infertility	25
How to conceive (including advice on sexual relations)	20
How to improve fertility	15
Female infertility	12
Treatments for infertility	10
Assisted reproductive technologies	6
Male infertility	4
Other	8

study has yielded practical insights that can be utilized in the development of improved patient education strategies. However, the study was limited by its cross-sectional design that recorded data at only one point along patients' information seeking histories. The reliance on self-selection of patients was to ensure that ethical guidelines were met. However, this made random sampling impossible, which is an additional limitation. There are numerous areas for further research into the knowledge and education needs of Indonesian infertility patients. These include investigating male patients' knowledge and information needs, exploring patients' use of the internet as an information source, examining the need for patient education specifically on infertility prevention, and investigating the effectiveness of different patient education techniques and doctor/patient communication styles.

4.2. Conclusion

The findings of this study highlight the imperative of providing comprehensive patient education for Indonesian infertility patients. The demand for further knowledge by 87% of the sample, and their poor levels of knowledge about the causes and treatment of infertility, underline this need. The fact that respondents indicated OBSGYN to be the most useful source of information points to the importance of maximizing opportunities for patient education within infertility consultations. This will require extending the length of standard fertility consultations to allow adequate time for education. Expanded patient education should incorporate respondents' priorities such as: the causes of infertility, how to conceive and how to improve fertility. STIs, smoking and age should be emphasized as major causes of infertility. Insights for developing appropriate printed education materials include: the use of lay language and the clear explication of medical terms, a greater utilization of images, better explanations of diagnosis protocols and treatment procedures, and more extensive coverage of infertility related knowledge. The statistically significant differences in access to information sources and levels of knowledge among patients indicates that patient education needs are likely to differ according to patients' level of schooling, which should be taken into account in curricula development and methods of patient education.

4.3. Practice implications

In order to ensure that comprehensive patient education becomes universal in Indonesian infertility care, a standard infertility patient education curriculum should be developed and piloted. When such a curriculum has been evaluated and validated, it should become compulsory within the medical education of fertility consultants. The provision of comprehensive patient education should also become requisite within infertility clinic practice guidelines.

Acknowledgements

We wish to thank the survey respondents for their time, the interview team for their dedication to ensuring the quality of the data collected, and the clinic administrators for allowing us to recruit through them. This work was supported by the Australian Research Council via a Future Fellowship awarded to Dr Linda Bennett to conduct research into compromised fertility in Indonesia.

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